eurocat
european surveillance of congenital anomalies

EUROCAT Statistical Monitoring Report – 2010

Executive Summary

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EUROCAT Central Registry
University of Ulster
Newtownabbey, Co Antrim
Northern Ireland, BT37 0QB

Tel: +44 28 9036 6639
Fax: +44 28 9036 8341
Email: eurocat@ulster.ac.uk
Web: www.eurocat-network.eu

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WHO Collaborating Centre for the Surveillance of Congenital Anomalies

EUROCAT 2010 Statistical Monitoring of Congenital Anomalies: Key Findings

Congenital anomalies are a leading cause of fetal death, infant mortality and morbidity in childhood. EUROCAT is a European network of population-based registries with the general objective of supporting the reduction of the public health burden of congenital anomalies by conducting coordinated epidemiological surveillance.

EUROCAT annually performs statistical monitoring for both trends and clusters in time in order to detect signals of new or increasing teratogenic exposures and monitor progress in the prevention of congenital anomalies. Total prevalence rates of 81 subgroups of congenital anomalies, including all cases of livebirths, stillbirths and late fetal deaths from 20 weeks gestational age, and terminations of pregnancy for fetal anomaly are monitored and reported. This report concerns the ten year period 2001-2010, including data from 24 EUROCAT registries. In the period 2001-2010, 82% of cases notified to the registries were liveborn, 2% were stillborn and 16% were terminations of pregnancy for fetal anomaly.

Our key findings concentrate on the pan-European analysis, which gives a snapshot of the situation in Europe. Within the main report, information on trends in the rates of congenital anomalies in individual registries is also presented.

Key findings

- In this year's pan-Europe analysis a *decreasing* trend was identified for **Neural tube defects (NTDs)** which declined on average by 1.7% per year to 9.42 per 10,000 births in 2009-2010. In particular, rates for **Spina bifida** declined on average by 2.1% per year to 4.67 in 2009-2010. The decreasing pan-Europe trend for NTDs suggests that public health measures, such as folic acid supplementation are becoming effective. However the decline has been shallow, and mainly occurred in the first half of the decade.

- Congenital heart defects (CHD) account for a third of all congenital anomaly cases. A *decreasing* trend was detected for the subgroup **CHD overall** which decreased on average by 0.6% per year to 62.37 per 10,000 births in 2009-2010. **Ventricular septal defect (VSD) and Atrial septal defect (ASD),** the most common and less severe types of CHD, both decreased; Potential explanations for the decline in CHD include folic acid supplementation and better management of maternal illness or

decline in maternal smoking. However, *increasing* trends were detected in some of the more severe types of CHD with **Tetralogy of Fallot**, a type of cyanotic congenital heart defect increasing on average by 2.3% per year to 3.26 per 10,000 births 2009-2010, and **Single ventricle** increasing on average by 5.9% per year to 0.74 per 10,000 births in 2009-2010.

- *Increasing* trends were found for several subgroups of digestive anomalies: **Oesophageal atresia with or without trachea-oesophageal fistula, Duodenal atresia and stenosis, Atresia and Stenosis of other parts of the small intestine.** The rare digestive system anomaly **Atresia of the bile ducts (biliary atresia)** *declined* markedly by an average of 9% per year to 0.17 per 10,000 births in 2009-2010. Maternal infective causes have been suggested as aetiological factors for biliary atresia.

- For the fourth consecutive year of pan-Europe monitoring an *increasing* trend was observed for the abdominal wall defect **Gastroschisis**, a rare type of defect that requires corrective surgery at birth. An average increase of 1.6 % per year was detected, with average rates rising to 2.87 per 10,000 births in 2009-2010. The largest increase in rates occurred in the early part of the decade. Gastroschisis is associated with risk factors such as low socioeconomic status (SES), young maternal age, low maternal body mass index (BMI) and maternal smoking. Four out of five registries with the highest prevalence rates for this anomaly were located in the UK. More directed action, particularly in the UK, is needed to address this public health concern.

- There was an *increasing* trend for the very rare anomaly **Complete absence of a limb**, with rates increasing on average by 7.8% per year to 0.22 per 10,000 births in 2009-2010. However this occurred in the context of a *decreasing* trend for **Upper limb reduction.** The data are being validated to make sure that this is not a classification problem.

- As in the previous report the three main chromosomal trisomy syndromes *increased* in prevalence. **Down syndrome/trisomy 21** increased on average by 1.1% per year to 22.38, **Patau syndrome/trisomy 13** by 2.4% per year to 2.09 and **Edward syndrome/trisomy 18** by 2.3% per year to 5.56 per 10,000 births in 2009-2010.

Following adjustment for maternal age these trends were no longer present, indicating that increases in trisomy syndromes in general are associated with rises in the proportion of women delaying child birth until later in life.

Clusters

Whilst the cluster analysis did not identify any clusters thought to be of immediate concern, a number (n=8) could not be explained by information held within the registries. The registries reported that these clusters, identified in the period 2009-2010, would remain under surveillance.

Conclusion

The statistical monitoring of trends and clusters is fundamental to the primary prevention of congenital anomalies, providing timely information on the stability and change in rates. Primary prevention of congenital anomalies continues to be a key objective of the EUROCAT network, and is reflected in the current ethos of the Joint Action between the European Union and Member States.